

## Paper 1: *DRAFT* Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 26 June 2019

### Present:

Stephen Holgate (SH) – Chair  
 Jim Wilson (JM)  
 Countess of Mar (MM)

Charles Shepherd (CS)  
 Deb Brown (DB)

Gabrielle Murphy (GM)  
 Anna Gregorowski (AG)

### Attended by phone

Opal Webster-Philp (OWP)  
 Colin Smith (CPS)  
 Craig Bullock (CB)

Sam Bromiley (SB)  
 Chris Ponting (CP)  
 Carmine Pariente (CPa)

Jo Elson (JE)  
 Neil Harrison (NH)

### Apologies

Mark Jones (MJ)  
 Patrick Chinnery (PC)

Neha Issar-Brown (NIB)  
 Sonya Chowdhury (SC)

Stephen Meader (SM)

	Agenda Item	Action
	<p><b>Welcome &amp; Introductions</b>            SH opened the meeting and introductions made.</p>	
1	<p><b>Minutes and Matters Arising</b></p> <p>Slight amendments made to the minutes for accuracy, including removing GM as lead for PR Working Group.</p> <p>JM referenced ToR and the need to co opt members onto the working groups. Agreed this would be minuted.</p> <p><b>Decision</b>            The Board approved the minutes of the last meeting as an accurate record of the meeting</p>	
2	<p><b>MRC Strategy Board</b></p> <p>SH updated the group on the application to the MRC. They have a strategy board meeting in July. (8<sup>th</sup> and 9<sup>th</sup>).</p> <p>SH will email MRC and state that people in the M.E./CFS community would like to know more about the plans and that the CMRC Board are looking to draft a statement once Strategy Board minutes are released.</p> <p>CP spoke about the need to prepare for future NIHR and MRC applications in case of approval in July. Board acknowledged that their remit does not</p>	SH

	<p>extend to putting forward applications for funding but seek and encourage collaborative work among researchers.</p> <p>JM to circulate other additions to terms of reference to the other board members.</p>	JM
3	<p><b>CMRC Working Groups</b></p> <ul style="list-style-type: none"> <li>• Medical Education Group: CS updated the group. New members have been co-opted on including a physiotherapist to talk about training they receive. Looking to get other health professionals involved. Special thanks to Nina Muirhead for her hard work on this.</li> <li>• Priority setting partnership: SH updated that SC will be pursuing this upon her return.</li> <li>• Omics and Big Data. CPS talked about ongoing genetics studies and informed group on a study he is looking for funding for.</li> <li>• Mitochondrial biology: JE gave an update on the work being done by the group and the areas being looked into.</li> <li>• Immunology: SH to speak to CPa and see what help he can offer to progress things and offer support.</li> <li>• PR: OWP talked about her paper and the PR working group. There is a need for us to communicate better with each other and the M.E. community. It was agreed that there is a need to communicate the science. MM to chair the group.</li> </ul> <p><b>Action</b> - Board agreed that the minutes of the working groups will be distributed to the board alongside papers for the meeting.</p>	
4	<p><b>Conference</b></p> <p>SB confirmed the conference will be Tuesday 10<sup>th</sup> and Wednesday 11<sup>th</sup> of March 2020 in Bristol at the same venue (Future Inn Bristol).</p> <p>SH detailed that financial support for the conference was received from MRC and Versus Arthritis previously. CB confirmed that Versus Arthritis are happy to contribute again.</p> <p>SH confirmed that he has been waiting for confirmation of funds before invites are sent out. SB suggested a working group be formed to progress things outside of the Board meeting.</p> <p>GM highlighted that work on abstracts would need to be done soon to increase the calibre. Someone in the working group to be a lead on the abstracts.</p>	

	<b>Action</b> - SB to set up working group for the conference. This will involve CB, NH, GB, CS, DB and a representative of the PAG.	SB
5	<p><b>Budget</b></p> <p>JM queried how much the PAG have in their budget. SB to look into and report back to JM.</p> <p><b>Action</b> – SB to provide figures for PAG ahead of the next board meeting.</p>	SB
6	<p><b>AOB</b></p> <p>None</p>	

*Minutes taken by SB 26.06.19*

*Approved by SH 05.07.19*